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Patient, Partner, and Physician

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"Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. This project is using a cross-sectional survey to explore the role of the patient, partner and physician in treatment decisions and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. Many valuable steps have been taken in the first year of this grant, including the development of a pilot questionnaire, administration of the pilot questionnaire, development of the protocol for the study and development of patient, spouse and physician questionnaires. Enrollment for the study began in November, 2000.

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Introduction

"Treatment Decisions in Localized Prostate Cancer: Patient, Partner and Physician," is a project that aims to develop and refine an innovative new model of prostate cancer decision making, that will form the foundation of a research and clinical program to understand, support and improve decision making in prostate cancer. We use a cross-sectional survey of patients, their spouses and their physicians to explore the role of the patient, partner and physician in treatment decisions, and to examine the effect of preferences, perceived preferences, and actual preferences on treatment decisions, decision satisfaction and decision process. By characterizing the role of the partner and the presence of significant misperceptions in the triad, and explicating the process of decision making under conditions of routine care, results of this project will serve as a basis for launching a research program in prostate cancer decision making. The guiding assumption of this work is that facilitation of communication and identification and resolution of misperceptions in the patient-partner-physician triad will improve patient satisfaction in decision making concerning localized prostate cancer.

Body

Task 1: Focus group discussions

Task 1 has been completed, as reported in our 2001 Annual Report

Task 2: Development of Survey Instruments

Task 2 has been completed, as we reported in our 2001 Annual Report. A final patient survey, partner survey, and doctor survey are included in his report (Appendix A, B and C).

Task 3: Preparation of Interim Reports and Manuscripts

The annual report is provided here.

Task 4: Cross-sectional survey

Identification and recruitment of subjects

This task is complete, as we reported in our 2001 Annual Report.

Enrolling subjects

In November 2000, we began identifying consecutive patients and enrolling them in our study. To date, we have identified 90 patients from the Hospital at the University of Pennsylvania (HUP) and 102 patients from the Philadelphia Veterans' Affairs Medical Center (VA).

At HUP, 23 patients have been excluded: 2 because of mental disorders, 18 have declined participation, and 3 could not be contacted by telephone. Of the 61 HUP patients from whom we obtained oral, witnessed consent to participation, 43 (70%) completed study questionnaires. Thirty-three of these 43 patients have spouses, and 29 (88%) of the spouses completed a spouse questionnaire.

At the VA, 27 patients have been excluded: 7 because of mental disorders, 12 have declined participation, and 8 could not be contacted by telephone. Of the 55 VA patients from whom we obtained oral, witnessed consent to participation, 29 (53%) completed study questionnaires. Eighteen of these 29 patients have spouses, and 15 (83%) of the spouses completed a spouse questionnaire. The 8 physicians at the VA have completed questionnaires about 67 of their patients.

Key Research Accomplishments

- Continual accrual of newly diagnosed prostate cancer patients and data collection.

Reportable Outcomes

- Three abstracts submitted to University of Pennsylvania Cancer Center Annual Scientific Symposium and Retreat. (Abstracts below.)

ABSTRACT I:

TREATMENT DECISION FACTORS IN MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. How do patients weigh the many factors involved in prostate cancer treatment decisions and are these factors weighed differentially in those who choose surgery versus a nonsurgical treatment option? We investigated the importance of a series of decision factors in patients with newly diagnosed prostate cancer just after they had made their treatment decision. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=72). Table 1 shows the importance of each decision factor to all subjects, and a comparison of the importance of each decision factor to those who chose surgery versus those who chose a nonsurgical treatment. More than 85% of subjects reported that longevity, feeling certain that the cancer is completely gone, the "track record" of the treatment and the spouse's opinion were very or extremely important in their decision. Chi Square tests comparing the importance of decision factors in those who chose surgery versus those who chose nonsurgical treatments revealed that the treatment's "track record" and impotence were rated as very or extremely important significantly more often in men choosing surgery ($p < .03$ for both comparisons). Keeping one's body intact and the cost of treatment were rated as very or extremely important significantly more often in men choosing a nonsurgical treatment ($p < .02$ for both comparisons). This study highlights several factors that influence decisions about treatment for localized prostate cancer. In the next year, we will continue to accrue patients and assess the relationship between these factors, treatment decisions, and long-term outcomes, such as decision satisfaction, satisfaction with treatment outcome, and quality of life.

Table 1. Importance of decision factors in all patients, and in patients choosing surgery versus a nonsurgical treatment

| Decision Factor | % RESPONDING "VERY OR EXTREMELY IMPORTANT" | | | |
|--|--|-------------------------|--|----------------------------|
| | All patients (n=72) | Chose surgery (n=36) | Chose nonsurgical treatment (n=36) | χ^2 test (p value) |
| Longevity | 89 | 92 | 86 | >.05 |
| Feeling certain that cancer is completely gone | 87 | 94 | 79 | .06 |
| "Track record" of treatment | 86 | 97 | 74 | .005 |
| Spouse's opinion | 86 | 90 | 79 | >.05 |
| Urologist's opinion | 83 | 81 | 86 | >.05 |
| Incontinence | 83 | 78 | 89 | >.05 |
| How quickly the treatment works | 67 | 72 | 61 | >.05 |
| Impotence | 63 | 75 | 50 | .03 |
| Primary care doctor's opinion | 59 | 56 | 63 | >.05 |
| Keeping my body intact | 56 | 41 | 69 | .02 |
| Recovery time from treatment | 51 | 44 | 57 | >.05 |
| Avoiding losing identity as a man | 51 | 43 | 59 | >.05 |
| Discomfort of the treatment | 42 | 40 | 44 | >.05 |
| Time it takes to get treatment | 39 | 43 | 35 | >.05 |
| Family member's opinion | 35 | 26 | 45 | >.05 |
| Opinion of friend who has or had prostate cancer | 35 | 32 | 38 | >.05 |
| Risks of anesthesia | 33 | 33 | 33 | >.05 |
| Cost of treatment | 20 | 5 | 34 | .002 |

ABSTRACT II:

INFORMATION-GATHERING PROCESS AND KNOWLEDGE OF TREATMENT OPTIONS IN MEN MAKING PROSTATE CANCER TREATMENT DECISIONS

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and the high-stakes, value-laden trade offs between higher survival rates and treatment side effects. What is the process that patients go through to gather information about their treatment options in order to make this difficult decision and how well informed are patients at the end of this process? We investigated the information-gathering process and resulting knowledge of treatment options in patients with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (n=72) after a treatment decision had been made. Nearly all patients report getting information about treatment options from their urologist (93%), although 42% report wishing they had received more information from the urologist. The timing of this discussion varied, occurring before biopsy results were available for 27%, during the same conversation when biopsy results were told for 24% and in a conversation after biopsy results were told for 49%. Eighteen percent of patients reported getting a second opinion from another urologist and 67% report consulting with a radiation oncologist. Many patients also report getting information from their primary care doctor (58%), a friend/acquaintance who is a doctor (22%), prostate cancer survivors (57%), the internet (46%) and books/medical journals (59%). However, as shown in Figure 1, at the end of this information-gathering process, after patients had made their treatment decision, some patients report not having heard of some of the common treatment options. Over the next year, we will continue to accrue patients and explore potential causes of knowledge gaps, including patient ineligibility for a given treatment, patient sociodemographic characteristics, and provider characteristics.

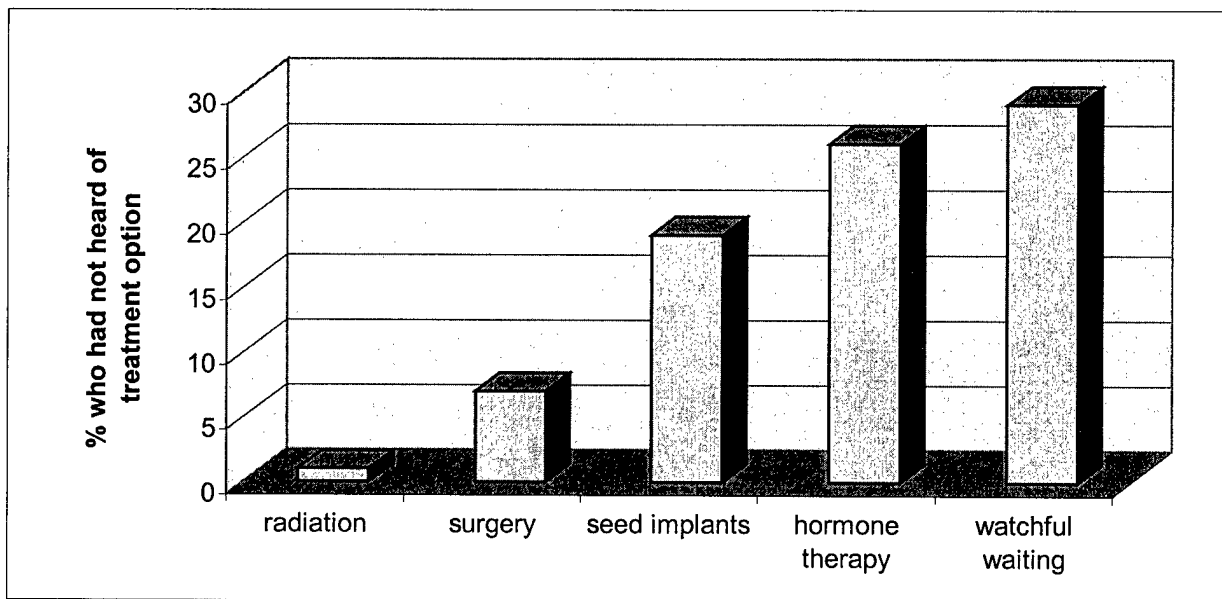


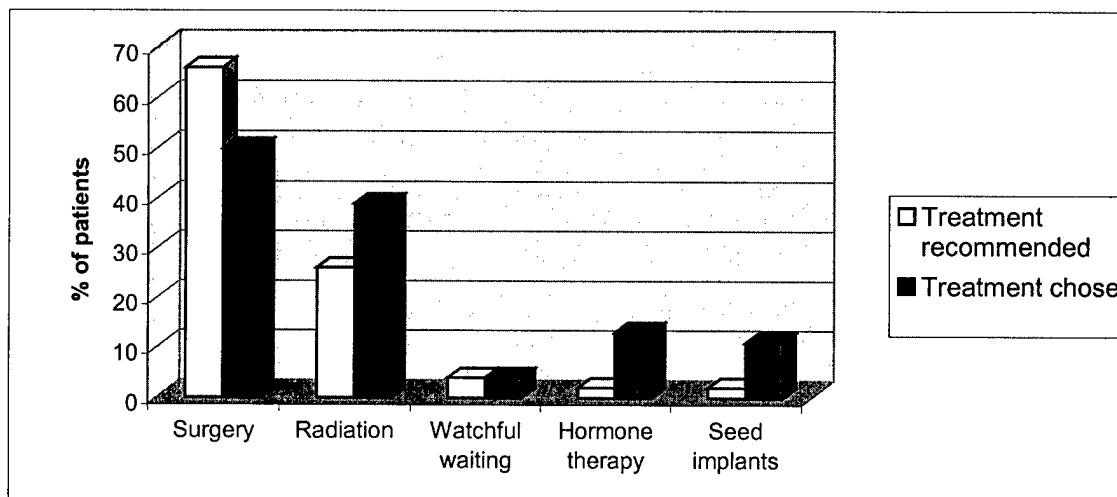
Figure 1. Patient knowledge of treatment options

ABSTRACT III:

THE ROLE OF UROLOGISTS' RECOMMENDATIONS IN TREATMENT DECISIONS OF MEN WITH NEWLY DIAGNOSED PROSTATE CANCER

Andrea D. Gurmankin, Adam Kaufman, Peter A. Ubel, James C. Coyne, S. Bruce Malkowicz, Katrina Armstrong

Prostate cancer treatment decisions can be difficult for patients because of the absence of a dominant treatment option and high-stakes, value-laden trade offs between higher survival rates and treatment side effects. Physician recommendations can have a complex role in these medical decisions. On one hand, the difficulty of the decision may make patients more reliant on their physician's recommendation. On the other hand, the value-laden nature of the decision may lead patients to disregard the recommendation and to make their own treatment decision. In this study, we explored the role of the urologist's recommendation in the treatment decisions of men with newly diagnosed prostate cancer. After obtaining written consent, surveys were mailed to consecutive patients at the Hospital of the University of Pennsylvania and the Philadelphia Veteran's Affairs Medical Center (VA) (n=72) after a treatment decision had been made. The 8 urologists of the VA patients also completed a survey about each of their newly diagnosed prostate cancer patients (n=8, who completed surveys for 64 patients). Eighty-five percent of patients report wanting to hear their urologist's recommendation, and 82% report receiving a recommendation, 59% of which were perceived to be very or extremely strong. The figure shows the percent of patients who report receiving a recommendation for each treatment option and the percent who chose each treatment option. Sixty-six percent of patients received a recommendation for surgery, 26% for radiation, 4% for watchful waiting, 2% for hormone therapy and 2% for seed implants. More patients than physicians believed that the patient had made the final treatment decision (74% versus 43% respectively). Although most patients report having made the final treatment decision, our data suggest that the physicians' recommendations nevertheless played a significant role in patients' treatment decisions. Over the next year, we will continue accruing patients (and at the VA, their respective physicians) and exploring the relationships between the role of the physician recommendation and patient characteristics and outcomes, such as decision satisfaction.



Conclusions

The past year has been productive and informative for this study. We have continued to enroll subjects into our study and have achieved an overall response rate of 62% across both hospitals. We have begun to conduct preliminary analyses of the data and have submitted abstracts for submission to relevant conferences.

Appendix A: Patient survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOU
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.

Subject Name: _____ Date: _____

Title of Study: Men's Health Care Decision Making StudyPrincipal Investigator: Bruce Malkowicz, M.D. VAMC: Philadelphia

PATIENT CONSENT FORM

Men's Health Care Decision Making Study

1. **Purpose of study and how long it will last:** I am being asked to participate in a research study to understand how men's health care decisions are made. The overall goal of the study is to develop ways to help patients and partners make the best decision.
2. **Description of the study including procedures to be used:** My participation in this study will involve filling out a survey that will be mailed to my home. This survey will ask about my feelings about my health care decisions. The alternative procedure to participation in this study is no survey.
3. **Description of any procedures that may result in discomfort or inconvenience:** The only inconvenience involved is the time requested to participate.
4. **Expected risks of study:** The risk to me is only an unlikely chance of breach of confidentiality.
5. **Measures to avoid risks:** Strict confidentiality measures will be taken at all times. My name and any identifying information will never appear on my questionnaire or in a data file with my responses, the questionnaire and data file will remain locked up at all times. The file with identifying information will be destroyed at the completion of the study. The file with identifying information will be destroyed at the completion of the study. If any publication or presentations results from this research, you will not be identified by name.
6. **Expected benefits of study:** The direct benefits to me from this study are none. However, the results of the study may benefit all men facing health care decisions.
7. **Other treatment available:** N/A

SUBJECT'S IDENTIFICATION (I.D. plate or give name-last, first, middle)

I have read and understood this
page of the consent form.

Subject initials _____

Witness initials _____

Continued →

8. **Use of research results:** I understand that all information collected in this trial will be kept strictly confidential except as may be required by law. No one outside of the study personnel will know the reason for my involvement in the study. If any publication results from this research, I will not be identified by name or in any form that could lead to my personal identification.

9. **Special circumstances:** No special circumstances.

Subject name

Subject signature

Subject address

Witness name

Witness signature

Instructions

This questionnaire asks about your experiences with the diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential. It is important that you follow these guidelines when filling out this questionnaire:

1. Please fill it out and return it to us **AFTER** you have made your prostate cancer treatment decision but **BEFORE** you have begun treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc). But if you have already begun treatment, please fill out the questionnaire anyway.
2. Please fill out this questionnaire without talking to your partner. We are interested in **YOUR** thoughts, even on the questions that ask about your partner. So please do not get any information or input from your partner while filling out the questionnaire.
3. Please answer every question to the best of your ability, even if you are unsure of your response.

If you have any questions, please feel free to contact Andrea Gurmankin at 215 573-9722. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

Who is your urologist? _____ (Your doctor will never see your responses)

Part A. The first set of questions asks about your treatment decision.

- 1) Which of the following possible treatments for prostate cancer have you **heard** of?
(check **all** that you have heard of)
 - ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
 - ☐ Radiation therapy
 - ☐ Seed implants (Brachytherapy)
 - ☐ Hormone therapy
 - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- 2) Which treatment have you chosen? (check **all** that apply)
 - ☐ Surgery
 - ☐ Radiation therapy
 - ☐ Watchful waiting
 - ☐ Seed implants
 - ☐ Hormone therapy
 - ☐ Other (Please explain):
- 3) Approximately when did you make your final decision about which treatment you would get for your prostate cancer? This includes deciding on watchful waiting. (Please just give your best estimate).
____/____/____
- 4) Approximately when did you begin treatment or when do you expect to begin treatment for prostate cancer?
____/____/____

5) Please tell us how important each of the following factors were in your prostate cancer treatment decision, and **then circle the one that was the most important factor** in your decision.

| | Extremely important | Very important | Somewhat important | Slightly important | Not at all important |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) possibility of impotence (inability to get or maintain an erection) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) possibility of incontinence (trouble controlling your urine) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) risks of anesthesia (the medicine given to patients to put them to sleep during surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) feeling certain that the cancer is completely gone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) keeping my body intact | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) avoiding losing my identity as a man | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g) desire to live as long as possible | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) cost of the treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) discomfort of the treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j) time it takes to get the treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k) how long it takes to recover from the treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l) "track record" of the treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m) how quickly the treatment works | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n) my urologist's opinion | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o) my primary care doctor's opinion | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p) my partner's opinion (<i>leave blank if you don't have a partner</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q) another family member's opinion (how are you related to this person?): _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r) opinion of a friend or acquaintance who has or has had prostate cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| s) information from other sources (what sources?): _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t) other (please explain): _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 6) Now please circle the letter beside the one factor listed **above in question 5** that was the **most important factor** in your treatment decision.

- 7) What have you done to get information about your treatment options? (*check all that apply*)
- ☐ Speak to my doctor
 Which doctor(s)? ☐ Urologist ☐ Primary care doctor ☐ Other
☐ Speak to friend/acquaintance who is a doctor
☐ Speak to prostate cancer survivors
☐ Get information on the internet
☐ Get information in books/medical journals
☐ Other (Please explain below where else you got information):
- 8) Which statement best describes how much medical information you want?
- ☐ I want *only* the information needed to care for myself properly
☐ I want additional information only if it is *good* news
☐ I want as *much* information as possible, good and bad
- 9) Which statement best describes the role you want to play in your medical decisions?
- ☐ I prefer to leave the decision to my doctor
☐ I prefer that my doctor make the final decision after seriously considering my opinion
☐ I prefer that my doctor and I share responsibility for making the decision
☐ I prefer to make the final decision after seriously considering my doctor's opinion
☐ I prefer to make the final decision on the basis of the facts I learn from my doctor and elsewhere, without considering my doctor's opinion

Part B. The next questions ask about when you were first diagnosed with prostate cancer.

- 1) Which doctor did you **first** speak to about whether you should get a biopsy to look for prostate cancer?
- ☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
☐ A urologist ☐ Other (Please explain):
- 2) When your doctor mentioned getting a prostate biopsy, did he/she **ask your opinion** about the idea?
- ☐ Yes ☐ No
- 3) Which doctor did you **first** speak to about your treatment options for prostate cancer?
- ☐ My primary care doctor ☐ A friend/acquaintance who is a doctor
☐ A urologist ☐ Other (please explain):
- 4) When did this conversation occur?
- ☐ during an appointment or conversation **before I got my biopsy results**
☐ **during** the same appointment or conversation in which I got my biopsy results
☐ during an appointment or conversation at some point **after I got my biopsy results**
☐ Other (please explain):
- 5) Was your partner present during this conversation?
- ☐ Yes ☐ No ☐ I have no partner

If the first time you talked to a doctor about treatment options was NOT with a urologist:

- 6) a) When was the main conversation you had with a urologist about your treatment options?
- ☐ during an appointment or conversation **before I got my biopsy results**
 - ☐ **during** the same appointment or conversation in which I **got my biopsy results**
 - ☐ during an appointment or conversation at some point **after I got my biopsy results**
 - ☐ Not applicable
 - ☐ Other (please explain):
- b) Was your partner present during this conversation about treatment options with the urologist?
- ☐ Yes ☐ No ☐ I have no partner

Part C. The next set of questions asks more about your conversation with your urologist about treatment options. If you have not yet spoken to your urologist about treatment options, please skip to Part D.

- 1) Approximately what was the date of your conversation with your urologist about your treatment options? (please give your best estimate) ____/____/____

- 2) About how much time did you spend talking with the urologist about your treatment options? (please give your best estimate) ____ minutes

- 3) Would you have preferred to spend more or less time talking with the urologist? (Please circle a number below)

| | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |

- 4) Did the urologist mention the option of →

- | | | |
|-------------------------------|------------------------------|-----------------------------|
| a) getting surgery? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| b) getting radiation therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| c) getting seed implants? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| d) getting hormone therapy? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| e) watchful waiting? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

- 5) Would you have preferred more or less information from the urologist? (Please circle a number below)

| | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |

- 6) If you had any questions for the urologist, did you feel free to ask your questions?
- ☐ I did not have any questions ☐ Yes ☐ No → Why not?:

- 7) Did your urologist give you **information about your chance of cure** using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?
☐ No numbers/only words ☐ Some numbers/some words
☐ Only numbers/no words ☐ No information given about chance of cure
- 8) Would you have preferred that your doctor use words, numbers or both to explain your chance of cure?
☐ Words ☐ Numbers ☐ Both ☐ No preference
- 9) Did the urologist recommend a particular treatment to you? ☐ Yes ☐ No

If yes →

a) What was the urologist's primary treatment recommendation?

- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (Please explain):

b) How strong was the urologist's recommendation? (*circle one number*)

- | | | | | |
|----------------------|--------------------|--------------------|----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all strong | Slightly strong | Somewhat strong | Very strong | Extremely strong |

- 10) Did you want the urologist to provide a recommendation? ☐ Yes ☐ No
- 11) Which treatment option did you favor BEFORE hearing the urologist's recommendation?
☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (Please explain):
- 12) Did the urologist suggest that you speak to a radiation oncologist? ☐ Yes ☐ No
- 13) Did you speak with a radiation oncologist? ☐ Yes ☐ No
- 14) Did you get a second opinion from another urologist? ☐ Yes ☐ No
- 15) Which of the following best describes how the decision about your prostate cancer treatment was made?
☐ My urologist made the final decision
☐ My urologist made the final decision after seriously considering my opinion
☐ My urologist and I shared responsibility for the final decision
☐ I made the final decision after seriously considering my urologist's opinion
☐ I made the final decision on the basis of the facts I learned from my urologist and elsewhere, without considering my urologist's opinion

Part D. The next questions ask your thoughts about different treatments and side effects.

| 1) How concerned are <u>you</u> about: | Extremely concerned | Very concerned | Somewhat concerned | Slightly concerned | Not at all concerned |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) experiencing impotence (trouble getting or maintaining an erection) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) experiencing incontinence (trouble controlling your urine) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) experiencing risks of anesthesia (the medicine given to patients to put them to sleep during surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) getting the best chance of cure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2) Please rate what you think your chance of **impotence** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3) Please rate what you think your chance of **incontinence** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4) Please rate what you think your chance of **cure** would be if you were to get **each** of the following treatments. For each one, assume you are **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Part E. Next we ask about what you think YOUR PARTNER thinks about different treatment options. We also ask about the discussions you two had about your options. If you do not have a partner, skip to Part F. Please remember to respond without input from your partner.

| 1) How concerned <u>do you think your partner</u> is about you: | Extremely concerned | Very concerned | Somewhat concerned | Slightly concerned | Not at all concerned |
|--|----------------------------|--------------------------|---------------------------|---------------------------|-----------------------------|
| a) experiencing incontinence (trouble controlling your urine)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) experiencing impotence (trouble getting or maintaining an erection)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) getting the best chance of cure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2) Which treatment do **you think your partner** thinks has the best chance of cure for you?

- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner thinks
☐ They all have the same chance of cure

3) If it had been up to **your partner**, which treatment do you think she would have chosen for you?

- ☐ Surgery ☐ Radiation therapy ☐ Hormone therapy
☐ Watchful waiting ☐ Seed implants
☐ I don't know what my partner would have chosen
☐ Other (please explain):

4) How does **your partner** feel about the treatment that was chosen?

- ☐ Insisted that I get it ☐ Opposed the decision
☐ Supported the decision ☐ Insisted that I not get it
☐ I don't know how my partner feels
☐ Other (please explain):

Please continue to the next page →

- 5) How often did you and your partner discuss your treatment options? *(please circle a number below)*

| | | | | |
|-------|--------|--------------|-------------|------------|
| 1 | 2 | 3 | 4 | 5 |
| Never | Seldom | Now and then | Quite often | Very often |

- 6) Would you have preferred to discuss your treatment options with your partner more or less? *(please circle a number below)*

| | | | | |
|-----------|---------------|-----------------------|---------------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Much less | A little less | Neither more nor less | A little more | Much more |

If you responded "never" to question 5, skip to question 10. Otherwise, continue to question 7.

- 7) When you had these discussions about treatment options, who initiated them?
☐ Me ☐ My partner ☐ We both initiated some of the discussions.

- 8) How satisfied were you with those discussions? *(please circle a number below)*

| | | | | |
|-------------------|-----------------------|------------------------------------|--------------------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Very dissatisfied | Somewhat dissatisfied | Neither satisfied nor dissatisfied | Somewhat satisfied | Very satisfied |

- 9) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? *(please circle a number below)*

| | | | | |
|-------|--------|--------------|-------------|------------|
| 1 | 2 | 3 | 4 | 5 |
| Never | Seldom | Now and then | Quite often | Very often |

- 10) How strongly did you want your partner's opinion to be factored into your treatment decision? *(please circle a number below)*

| | | | | |
|------------|----------|----------|------|-----------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all | A little | Somewhat | Very | Extremely |

Please continue to the next page →

| | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 11) The following statements focus on the way your partner deals with the fact that you have prostate cancer. Please indicate to what extent your partner does or does not act in the ways described. | | | | | |
| | Never | Seldom | Now and then | Quite often | Very often |
| a) My partner tries to discuss it with me openly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) My partner asks me how I feel | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) When something bothers me, my partner tries to discuss the problem | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) My partner is full of understanding towards me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) My partner makes me feel that I'm not alone in this | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) My partner tries to persuade me to follow the doctor's instructions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g) My partner tries to hide his or her worries about me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) My partner tries to act as if nothing is the matter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) My partner gives in when I make an issue of something | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j) My partner just waves my worries aside | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k) My partner does everything to prevent me from thinking about my disease | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l) My partner can't endure me being concerned and acts as if she doesn't notice my worries | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m) My partner takes over as much of my work as possible | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Please continue to the next page →

Part F. This set of questions asks about your feelings of conflict over your prostate cancer treatment decision. The statements below are things that some people say when they have just made a difficult decision. Thinking about decision, please check the box that best matches how much you agree with each statement.

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|
| 1) I feel I have made an informed choice | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2) My decision shows what is most important for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3) I expect to stick to my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4) I am satisfied with my decision. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5) This decision was hard for me to make | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6) I was unsure what to do in this decision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7) It was clear what choice was best for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8) I am aware of the choices I have to manage my prostate cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9) I feel I know the benefits of the treatments for prostate cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10) I feel I know the risks and side effects of treatment for prostate cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11) I need more advice and information about the choices | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12) I know how important the benefits of the treatment for prostate cancer are to me in this decision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13) I felt pressure from others in making this decision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14) I had the right amount of support from others in making this decision | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Part G. The next questions ask about your background.

- 1) What is your age? _____ years
- 2) What is your race?
☐ African-American ☐ Caucasian ☐ Hispanic
☐ Asian-American ☐ Other (please specify) _____
- 3) What level of education have you completed? (*Circle one number*)
9 10 11 12 13 14 15 16 17 18 19 20 21+
high school college graduate school
- 4) Which of the following conditions have you had in the past 12 months?
(*check all that apply*)
☐ high blood pressure ☐ heart trouble
☐ diabetes ☐ emotional or mental illness
☐ stroke ☐ chronic bronchitis
☐ asthma ☐ arthritis or rheumatism
☐ cancer (other than prostate) ☐ epilepsy
☐ chronic nervous trouble ☐ tuberculosis
☐ hernia or rupture ☐ chronic liver problem
☐ drinking problems or alcoholism ☐ chronic gallbladder trouble
☐ stomach ulcer or duodenal ulcer
- 5) Are you currently experiencing impotence? ☐ Yes ☐ No
- 6) Are you currently experiencing incontinence? ☐ Yes ☐ No
- 7) Do you currently have health insurance? ☐ Yes ☐ No ☐ Not sure
- 7a) *If yes* ➤ please check the type of plan that best describes your current health insurance:
☐ Fee-for-service plan where you can go to any doctor or hospital
☐ HMO where your primary care doctor refers you to specialists
☐ PPO where you can go to any doctor or hospital on a list without getting a referral
☐ I don't know which type of plan I have

Part H. This section asks about your relationship with your partner. If you do not have a partner, skip to Part I.

1) Most people have some disagreements in their relationships. Below is a series of issues. We'd like you to tell us of any disagreement experienced between you and your partner over each of these issues in a typical month (this past month may not have been typical for you, since you were just diagnosed with prostate cancer). So for each issue, please tell us in a typical month, how much you have agreed or disagreed about....

| In a typical month, my partner and I have | Always agreed | Almost always agreed | Occasionally agreed | Frequently disagreed | Almost always disagreed | Always disagreed |
|--|--------------------------|-----------------------------|----------------------------|-----------------------------|--------------------------------|--------------------------|
| a) religious matters | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) demonstration of affection | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) sex relations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) conventionality (correct or proper behavior) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) making major decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) career decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 2) How often do you and your partner do the following things: | All the time | Most of the time | More often than not | Occasionally | Rarely | Never |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|--------------------------|
| a) discuss or consider divorce, separation, or terminating your relationship? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) regret that you married? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) quarrel? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) "get on each other's nerves?" | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Every day | Almost every day | Occasionally | Rarely | Never |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 3) How often do you and your partner engage in outside interests together? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| Below are some things that you and your partner might do. Please tell us how often you think they occur between you and your partner. | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | More than once a day | Once a day | Once or twice a week | Once or twice a month | Less than once a month | Never |
| 4) Have a stimulating exchange of ideas | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5) Calmly discuss something | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6) Work together on a project | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7) How often does your partner go with you to your doctors' appointments?

1 2 3 4 5

Never Once in a while Sometimes Frequently Always

8) How long have you and your partner been together? _____ years

Part I. This last section asks about your quality of life.

| 1) During the past four weeks how much of the time ... | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) have you been concerned or worried about loss of muscle tone? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) did you have negative feelings about the way your body looks? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) did you avoid being seen without a shirt on? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) did you feel that your body was getting soft and flabby? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) were you concerned or worried about difficulty getting or keeping an erection? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) did you wish you could regain your sexual ability? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g) did you feel frustrated about your sexual ability? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) did you feel despair over the loss of sexual ability? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Skip to question 3 if you do not have a partner

| 2) How true or false has each of the following statements been for you during the past four weeks? | Definitely true | Mostly true | Neither true no false | Mostly false | Definitely false |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) I felt uncomfortable when my partner wanted to hug or kiss me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) I felt affectionate about my partner. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) I felt that my partner was not satisfied with our sex life. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) I felt that my partner may want to turn to others for affection. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) My partner was worried about my cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) I worked hard to keep my partner from worrying about my health. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 3) How true or false has each of the following statements been for you during the past four weeks? | Definitely true | Mostly true | Neither true no false | Mostly false | Definitely false |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Since I've had cancer I feel that I have lost my ability to be aggressive. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) I feel that I've lost part of my manhood. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) I feel as if I'm going through a "change of life" like women do. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) I feel that what I say is not taken very seriously by others. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 4) During the past four weeks how much of the time ... | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) did you feel that your cancer kept you from being the friend you wanted to be? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) did you feel that other people don't really understand what it's like to have prostate cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) did you feel that you were a bother to other people? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) did you worry about eventually becoming unable to take care of yourself? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) did you worry about your cancer, but keep it to yourself? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| f) did you feel that others who are close to you try to hide their true feelings about your cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g) did you feel that others think less of you because of your health problems? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) have you felt weak and small? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) have you worried about the cancer spreading? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j) have you thought about your cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k) have you worried about dying soon? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l) have you been concerned about side-effects of your cancer treatment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m) have you felt that your cancer has given you a better outlook on your life? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n) have you felt that coping with your cancer has made you a stronger person? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o) have you wished that you could change your mind about the kind of treatment you chose for your prostate cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 5) How true or false has each of the following statements been for you during the past four weeks? | Definitely true | Mostly true | Neither true nor false | Mostly false | Definitely false |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) I feel that I would be better off if I had chosen another treatment for prostate cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) It bothers me that other men with prostate cancer get treatment that is very different from what I will receive. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Thank you for your participation. Please mail the completed survey in the enclosed, stamped, addressed envelope.

Appendix B: Partner survey

**MEN'S HEALTH CARE
DECISION MAKING
STUDY**

**FOR YOUR
PARTNER
TO COMPLETE**

Thank you very much for your help.

Please return in the enclosed envelope.



Subject Name: _____ Date: _____

Title of Study: Men's Health Care Decision Making StudyPrincipal Investigator: Bruce Malkowicz, M.D. VAMC: Philadelphia

PARTNER CONSENT FORM

Men's Health Care Decision Making Study

1. **Purpose of study and how long it will last:** I am being asked to participate in a research study to understand how men's health care decisions are made. The overall goal of the study is to develop ways to help patients and partners make the best decision.
2. **Description of the study including procedures to be used:** My participation in this study will involve filling out a survey that will be mailed to my home. This survey will ask about my feelings about my partner's health care decisions. The alternative procedure to participation in this study is no survey.
3. **Description of any procedures that may result in discomfort or inconvenience:** The only inconvenience involved is the time requested to participate.
4. **Expected risks of study:** The risk to me is only an unlikely chance of breach of confidentiality.
5. **Measures to avoid risks:** Strict confidentiality measures will be taken at all times. My name and any identifying information will never appear on my questionnaire or in a data file with my responses, the questionnaire and data file will remain locked up at all times, and will only be accessible to the Principle Investigator and the Project Manager. The file with identifying information will be destroyed at the completion of the study. If any publication or presentations results from this research, you will not be identified by name.
6. **Expected benefits of study:** The direct benefits to me from this study are none. However, the results of the study may benefit all men facing health care decisions.
7. **Other treatment available:** N/A

I have read and understood this
page of the consent form.

Subject initials _____

Witness initials _____

Continued →

SUBJECT'S IDENTIFICATION (I.D. plate or give name-last, first, middle)

8. **Use of research results:** I understand that all information collected in this trial will be kept strictly confidential except as may be required by law. No one outside of the study personnel will know the reason for my involvement in the study. If any publication results from this research, I will not be identified by name or in any form that could lead to my personal identification.

9. **Special circumstances:** No special circumstances.

Subject name

Subject signature

Subject address

Witness name

Witness signature

Instructions:

This questionnaire asks about your experiences with your spouse or partner's diagnosis of prostate cancer and deciding on a treatment. Your answers will be kept strictly confidential. It is extremely important that you follow these guidelines when filling out this questionnaire:

- 1. Please fill it out and return it to us AFTER your partner's treatment decision has been made but BEFORE your partner has begun or undergone treatment for prostate cancer (i.e. surgery, radiation, seed implants, etc). But if your partner has already begun treatment, please fill out the questionnaire anyway.**
- 2. Please fill out this questionnaire without any communication between you and your partner. We are interested in YOUR thoughts, even on the questions that ask about your partner. So please do not get any information or input from your spouse while filling out the questionnaire.**
- 3. Please answer every question to the best of your ability, even if you are unsure of your response.**

If you have any questions, please feel free to contact Andrea Gurmankin at 215 573 9722. Thank you in advance for your participation.

Date you are filling out this questionnaire: ____/____/____

- 1) Which of the following possible treatments for prostate cancer have you **heard** of?
(check **all** that you have heard of)
 - ☐ Surgery (Radical prostatectomy- procedure where they remove the prostate)
 - ☐ Radiation therapy
 - ☐ Seed implants (Brachytherapy)
 - ☐ Hormone therapy
 - ☐ Watchful waiting (No treatment, but getting regular blood tests to check on the status of the cancer)
- 2) Please rate what you think your partner's chance of **impotence** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 3) Please rate what you think your partner's chance of **incontinence** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 4) Please rate what you think your partner's chance of **cure** would be if he were to get **each** of the following treatments. For each one, assume he is **ONLY** getting that one treatment.

| | Not at all likely | Slightly likely | Somewhat likely | Very likely | Extremely likely |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) Radical prostatectomy (surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Hormone therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Seed implants | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Watchful waiting (no treatment) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Questions 5-8 ask about YOUR thoughts about different prostate cancer treatments and their possible side effects

| How concerned are <u>you</u> about your partner: | Extremely concerned | Very concerned | Somewhat concerned | Slightly concerned | Not at all concerned |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 5) experiencing impotence (trouble getting or maintaining an erection) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6) experiencing incontinence (trouble controlling his urine) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7) experiencing risks of anesthesia (the medicine given to patients to put them to sleep during surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8) getting the best chance of cure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 9) If it had been up to you, which treatment would you have chosen for your partner?
- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (please explain):

Questions 10-13 ask about YOUR thoughts about what your PARTNER thinks about different treatments and possible side effects. *Please remember to respond without input from your partner.*

| How concerned <u>do you think your partner</u> is about: | Extremely concerned | Very concerned | Somewhat concerned | Slightly concerned | Not at all concerned |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 10) experiencing incontinence (trouble controlling his urine)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11) experiencing impotence (trouble getting or maintaining an erection)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12) experiencing the risks of anesthesia (the medicine that they give to patients to put them to sleep during the surgery)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13) getting the best chance of cure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

14) Which treatment do you think your partner thinks has the best chance of cure for him?

- ☐ Surgery ☐ Radiation therapy ☐ Watchful waiting
☐ Seed implants ☐ Hormone therapy ☐ Other (please explain):

The next section asks about the discussions that you and your partner had about treatment options.

15) How often did you and your partner discuss his treatment options? (*please circle a number below*)

- 1 2 3 4 5
 Never Seldom Now and then Quite often Very often

16) Would you have preferred to discuss his treatment options more or less? (*please circle a number below*)

- 1 2 3 4 5
 Much less A little less Neither more nor less A little more Much more

If you responded "never" to question 15, skip to question 19. Otherwise, continue to question 17.

17) When you had these discussions about treatment options, who initiated them?

- ☐ Me ☐ My partner ☐ We both initiated some of the discussions.

18) How satisfied were you with those discussions? (*please circle a number below*)

- 1 2 3 4 5
 Very dissatisfied Somewhat dissatisfied Neither satisfied nor dissatisfied Somewhat satisfied Very satisfied

- 19) How often did you and your partner get into a disagreement or conflict over the issue of which treatment to choose? *(please circle a number below)*
- 1 2 3 4 5
 Never Seldom Now and then Quite often Very often

| The following statements focus on the way you deal with the fact that your partner has prostate cancer. Please indicate to what extent you do or do not act in the ways described. | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | Never | Seldom | Now and then | Quite often | Very often |
| 20) I try to discuss it with my partner openly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21) I ask my partner how he feels | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22) When something bothers my partner, I try to discuss the problem | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 23) I am full of understanding towards my partner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 24) I make my partner feel that he is not alone in this | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 25) I try to persuade my partner to follow the doctor's instructions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 26) I try to hide my worries about my partner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 27) I try to act as if nothing is the matter | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 28) I give in when my partner makes an issue of something | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 29) I just wave my partner's worries aside | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 30) I do everything to prevent my partner from thinking about his disease | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31) I can't endure my partner being concerned and act as if I do not notice my partner's worries. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32) I take over as much of my partner's work as possible. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 33) How strongly did you want your opinion to be factored into your partner's treatment decision? *(Circle a number below)*
- 1 2 3 4 5
 Not at all A little Somewhat Very Extremely
- 34) How satisfied are you with the information you have about your partner's prostate cancer diagnosis and treatment options? *(Circle a number below)*
- 1 2 3 4 5
 Very dissatisfied Somewhat dissatisfied Neither satisfied nor dissatisfied Somewhat satisfied Very satisfied

This last section asks a few questions about you.

35) What is your age? _____ years

36) What is your race?

☐ African-American

☐ Caucasian

☐ Hispanic

☐ Asian-American

☐ Other (please specify) _____

37) What level of education have you completed? (*Circle a number below*)

9 10 11 12

13 14 15 16

17 18 19 20 21+

high school

college

graduate school

**Thank you for your participation. Please mail the completed survey
in the enclosed, stamped, addressed envelope.**

Appendix C: Physician survey

Date ____ / ____ / ____

Patient name _____

Please fill out after telling patient of his positive prostate biopsy and his treatment options.

1) Which of the following treatment options did you mention to the patient?

getting surgery ☐ Yes ☐ No getting hormone therapy ☐ Yes ☐ No
getting radiation therapy ☐ Yes ☐ No watchful waiting ☐ Yes ☐ No
getting seed implants ☐ Yes ☐ No

2) Did you recommend a particular treatment to the patient? ☐ Yes ☐ No (If no, skip to #5)

3) What was your **primary** recommendation (check one)?

☐ Radical prostatectomy ☐ Radiation therapy ☐ Hormone therapy
☐ Brachytherapy ☐ Watchful waiting ☐ Other (Please explain):

4) How strong was your recommendation for this treatment option? (check one option)

☐ Not at all ☐ Slightly ☐ Somewhat ☐ Very ☐ Extremely
strong strong strong strong strong

5) Do you think the patient would have preferred more or less information from you? (choose one)

1 2 3 4 5
Much less A little Neither more A little Much more
less less nor less more

6) Do you think the patient asked all of the questions that he had? ☐ Yes ☐ No

7) Which statement best describes how much medical information this patient wants?

☐ He wants *only* the information needed to care for himself properly.
☐ He wants additional information only if it is *good* news.
☐ He wants as *much* information as possible, good and bad.

8) Which statement best describes the role this patient wants to play in his medical decisions?

☐ He prefers to leave the decision to his doctor
☐ He prefers that the doctor make the final decision after seriously considering his opinion
☐ He prefers that he and the doctor share responsibility for making the decision
☐ He prefers to make the final decision after seriously considering the doctor's opinion.
☐ He prefers to make the final decision on the basis of the facts he learns from the doctor and elsewhere, without considering the doctor's opinion.

9) Did you suggest that the patient speak to a radiation oncologist? ☐ Yes ☐ No

continue to next page →

WIN A DINNER AT LE BEC FIN

Every time you fill out a questionnaire, we will enter you in a raffle to win a \$150 gift certificate to Le Bec Fin. Write your name below, and we will enter this slip into the drawing. The next drawing will be in December, and we will contact the winner by email.

Name: _____ email (only necessary to give us once): _____

10) Compared to other newly diagnosed prostate cancer patients, how much did this patient ask questions or elicit information about his diagnosis, treatment options and/or prognosis?

1 2 3 4 5
 Much less A little less Neither more A little more Much more
 than others than others nor less than others than others

| 11) How concerned do you think this patient is about: | Extremely | Very | Somewhat | Slightly | Not at all | I don't know |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a) experiencing impotence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) experiencing incontinence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) experiencing risks of anesthesia | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) getting the best chance of cure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

12) Did you give the patient **information about his chance of cure** using **numbers** (for example, "a 2% chance") or **words** (for example, "a very small chance")?

- ☐ No numbers/only words ☐ Some numbers/some words
☐ Only numbers/no words ☐ No information given about chance of cure

13) Using the response options below, please rate what you think this patient's chance of **cure** would be if he were to get **each** of the following treatments? For each treatment, assume he is **ONLY** getting that one treatment. (Enter 1 for not at all likely, 2 for slightly likely, 3 for somewhat likely, 4 for very likely and 5 for extremely likely).

_____ Radical prostatectomy _____ Radiation therapy _____ Hormone therapy
 _____ Brachytherapy _____ Watchful waiting

14) Which best describes how the patient's treatment decision was made?

- ☐ I made the final decision
☐ I made the final decision after seriously considering the patient's opinion
☐ The patient and I shared responsibility for the final decision.
☐ The patient made the final decision after seriously considering my opinion.
☐ The patient made the final decision on the basis of the facts he learned from me and elsewhere, without considering my opinion.
☐ I don't know (because the patient made the decision with another doctor)
☐ The decision has not been made yet

Thank you for completing our questionnaire.